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ABSTRACT

The 1986 annual statistical report provides data from 46 states and territories on protection and advocacy for persons with developmental disabilities and on client assistance programs. The 1987 report, compiling data from 55 states and territories, provides, in addition, data on protection and advocacy for persons with mental illness. The reports begin with a brief outline of the purpose, goals, and administering agency for these programs. In the program area of protection and advocacy for persons with developmental disabilities and mental illness, categories of summarized data include: (1) number of clients served; (2) demographic data of clients served; (3) client impairments; (4) client living arrangements; and (4) case problem areas. For individuals with developmental disabilities, information is also provided on clients' substantial functional limitations. Concerning the client assistance programs, information on client case loads is summarized by demographics, client impairment, and case problems. A narrative summary contains anecdotal examples of client assistance, protection, and advocacy activities. A chart reflects appropriated levels of federal funding for these programs. The reports conclude with a list of state offices for protection and advocacy and for client assistance programs. (JDD)

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National Association of Protection and Advocacy Systems

Annual Statistical Report

1986

1987

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NAPAS

National Association of Protection and Advocacy Systems

1986

ANNUAL STATISTICAL REPORT

I. Protection & Advocacy for Persons with Developmental Disabilities

II. Client Assistance Program

III. Protection & Advocacy for Persons with Mental Illness

NAPAS
300 I Street, N.E., Suite 212
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May, 1988

Protection & Advocacy for Persons with Developmental Disabilities

This program was originally established by the Developmental Disabilities Act of 1977, which mandated that states provide advocacy services, including legal, administrative and other appropriate remedies, to protect the rights of individuals with disabilities. The 1986 fiscal appropriation by Congress for DD P&A activities was $14.6 million.

Developmental disabilities are defined by the federal government as chronic and attributable to mental and/or physical impairments which are evident prior to age twenty-two. These disabilities tend to be life-long and result in substantial limitations in three or more of the following major life activities: self care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living, and/or economic self-sufficiency.

Appendix I of this annual report summarizes the P&A DD activities undertaken by 46 states and territories for fiscal year 1986. Categories of summarized data include: (1) number of clients served; (2) non-client directed services; (3) demographic data of clients served; (4) clients' living arrangements; (5) client impairments; (6) clients' substantial functional limitations; and (7) case problem areas.

Client Assistance Program

Section 112(a) of the Rehabilitation Act of 1973, as amended by the Rehabilitation Act Amendments of 1984 (29 U.S.C. 732), mandated the establishment of Client Assistance Programs (CAPs), reflecting the belief of Congress that persons with disabilities require assistance in obtaining information and access to services provided under the Act. The purpose of CAPs is to advise vocational rehabilitation clients and client applicants about all available services under the Act; to assist them in their relationships with projects, programs, and facilities providing rehabilitation services through the Department of Vocational Rehabilitation (DVR) under the Act; and to assist in this process through the use of legal, administrative and other appropriate remedies to ensure the protection of rights of DVR clients. The CAP program for 1986 was authorized by Congress at $6.4 million.

In many cases, CAPs are designated as part of the P&A system but others are independent agencies or part of departments of vocational rehabilitation. The Governor of each state has the authority to designate CAP programs and is not allowed to redesignate CAP without demonstrating good cause.

The breakdown of CAP designation is as follows: 28 CAP agencies are externally designated to P&As; 11 CAPs are externally designated to other agencies; 1 CAP is externally designated to a for-profit agency (Alaska); 18 CAPs are internally designated to departments of vocational rehabilitation, and of these, 9 are housed inter-departmentally, 5 are subcontracted to other agencies by the department, and 4 subcontract to the state P&A system.

Protection and Advocacy for Persons with Mental Illness

Modeled after the DD P&A, the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (P.L. 99-319) was passed in May of that year. Similar to the DD P&A, the Act established a system that protects the rights of persons with mental illness under federal and state statutes. The individuals covered under the Act must reside in facilities which provide 24 hour care and treatment, or have been discharged from such a facility within the past 90 days. Monies became available in the end of 1986. Therefore no statistical information is available for FY 1986. 1987 represents the first full year of operation. The appropriation was $9.5 million for FY 1986 and $10.5 million for FY 1987.

P&A and CAP Mission

P&A and CAP staff consist of attorneys, social workers and other advocates who are capable of providing a full range of advocacy services including the ability to pursue legal, administrative and other appropriate remedies to protect the rights of clients. P&A programs must be independent of any service provider to assure conflict-free advocacy services. The Governor of each state designates both the P&A and CAP agencies to fulfill federal mandates and cannot redesignate the program without good cause.

P&A and CAP activities include: (1) investigating, negotiating or mediating solutions to problems expressed by persons with developmental disabilities, persons with mental illness or cients of DVRs, their families or agency representatives; (2) providing technical assistance to attorneys, governmental agencies and service providers; (3) providing legal counsel and litigation services to persons in this population and groups who are unable to attain adequate or appropriate legal services in their communities; and (4) training advocates, consumers, volunteers, professionals, and other parties.

The P&A system works with institutions, including residential care providers, public and private hospitals for persons with mental illness or mental retardation, public schools and state correctional facilities in addition to a host of other service providers and governmental offices. The P&A system also provides advice and technical assistance to attorneys on such issues as disability and mental health law as well as providing assistance to various boards, commissions and government officials.

The CAP program works with vocational rehabilitation agencies and other agencies which receive funds under the Rehabilitation Act.

This annual report summarizes client case load information by such categories as demographics, client impairment, and case problems as required by the federal administering agencies. Also included is an explanation of the P&A and CAP mandate. Attachments are as follows:

Appendix I ..... DD P&A Program

Appendix II..... CAP Program

Appendix III..... Narrative Summary

Appendix IV..... Program Funding Chart

Appendix V..... CAP & P&A Offices

P&A for Persons with Developmental Disabilities
1986 Annual Report

NOTE: The following figures are derived from total caseloads as reported by 46 states and territories.

CLIENTS SERVED

Number of Individual Clients Served	50,781
Number of Individuals Served Under Class Actions (Where Number is Known)	186,000
Information & Referrals	38,576
Number of People Receiving Education & Training	34,700

DEMOGRAPHIC DATA ON CLIENTS SERVED

I. Sex

		% of Total
Male	22,948	45%
Female	14,613	29%
Unreported	13,220	26%
Total	50,781	100%

II. Age of Clients Served:

Age	Total Clients	% of Total
0-4	2,082	4%
5-20	18,196	36%
21-64	14,878	29%
65+	1,895	4%
Unreported	13,730	27%
Total	50,781	100%

III. Geographic Location of Clients Served:

	Total Clients	% of Total
Urban (population of 50,000 or more)	19,269	37%
Rural (all other areas that have less than 50,000)	13,559	27%
Out of State (client's legal residence other than where P&A is located)	313	1%
Unreported	17,640	35%
Total	50,781	100%

IV. Client Living Arrangement:	Total	% of Total
Community Residential Home	2,250	4%
Foster Care	1,723	3%
Independent	3,027	6%
Nursing Home	1,462	3%
Parental or Other Family Home	16,759	33%
Public Institution	6,935	15%
Prison	200	0
State School	193	0
Private Educational Institution	445	1%
Other	1,936	4%
Unreported	15,851	31%
Total	50,781	100%

DISABILITY

V. Client Impairment:	Total	% of Total
Autism	946	2%
Cerebral Palsy	2,398	5%
Epilepsy	1,859	4%
Mental Illness	4,401	9%
Mental Retardation	14,150	28%
Multiple Sclerosis	250	0
Multiple Impaired	1,227	2%
Physical/Orthopedic	3,065	6%
Spina Bifida	202	0
Other	12,999	26%
Unreported or none	9,284	18%
Total	50,781	100%

VI. Client Substantial Functional Limitation:	Total	% of Total
Self Care	18,272	17%
Language	13,671	12%
Learning	19,808	18%
Mobility	8,868	8%
Self Direction	15,913	14%
Independent Living	16,662	15%
Economic Self Sufficiency	17,638	16%
Total	110,832*	100%

*Note that "client substantial functional limitation" exceeds total number of clients served. The federal definition of developmentally disabled requires 3 functional limitations.

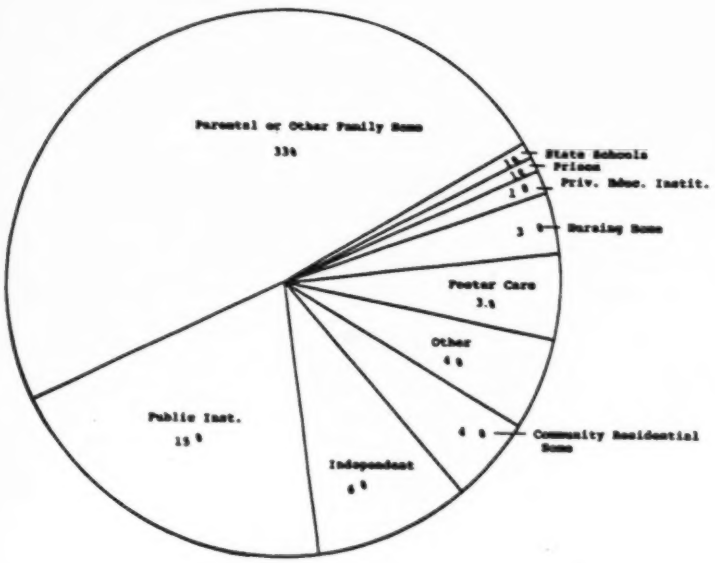
CASE PROBLEM AREAS

	Total	% of Total
Abuse/Neglect Exploitation	2,331	5%
Admission/Commitment to Institution	1,273	3%
Architectural Barriers	1,083	2%
Conditions in Facilities	1,107	2%
Consent	129	0
Contracts/Ownership of Property	177	0
Criminal Justice Issues	696	1%
Day Care	125	0
Education	14,031	28%
Employment	1,444	3%
Financial Entitlements	3,367	7%
Guardianship/Conservatorship	1,757	3%
Habilitation Services	3,662	7%
Housing	1,394	3%
Insurance	289	1%
Medical Services/and or Mental Health Services	1,711	3%
Records (access to, confidentiality of)	139	0
Rehabilitation Services	1,051	2%
Rights of Privacy	193	0
Sterilization	105	0
Transportation (non-education related)	1,031	2%
Voting	11	0
Wills & Estate Planning	164	0
Zoning	85	0
Other or Unreported (for example: foster care, respite care, legal harrassment)	13,426	25%
Total	50,781	100%

P&A for Persons with Developmental Disabilities

1986 Annual Report

Client Living Arrangement:



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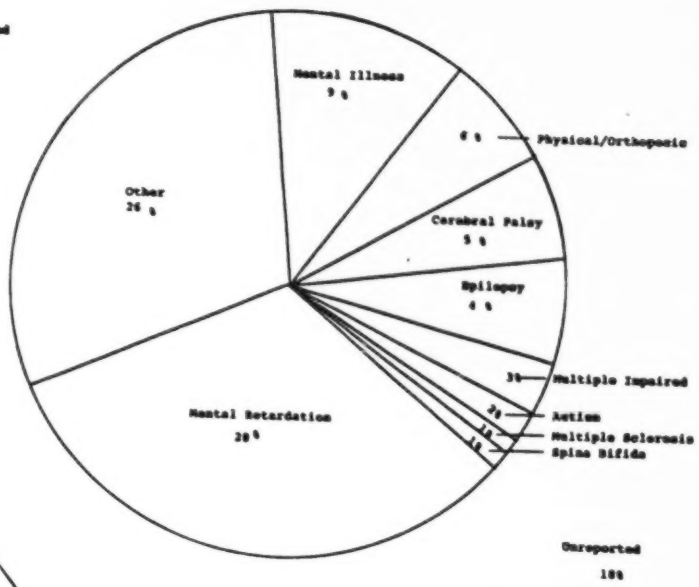

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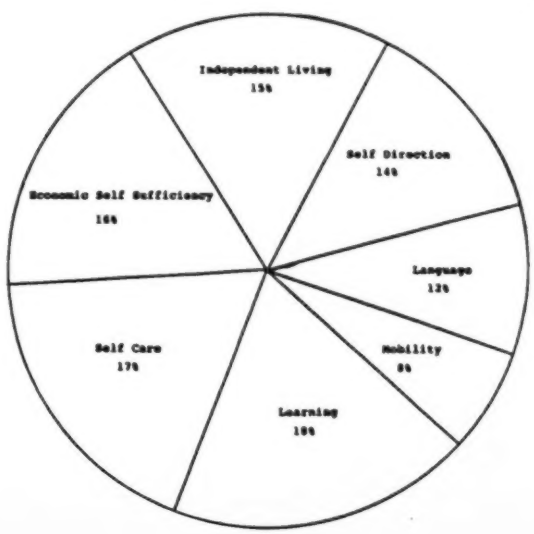


Appendix II

Client Assistance Program
1986 Annual Report
Page 1

The following statistics show total numbers of clients by categorical area, including types of individuals served, source of person's concern, problem areas, major disabling conditions, and types of services provided.

TOTAL CLIENTS SERVED

Total Clients	Information & Referral
13,466	25,548

PROGRAM DATA

Types of Individuals Served:	Total	% of Total
Applicants for VR	13,251	60%
Clients of VR Agencies (before IWRP)	2,288	11%
Clients of VR Agencies (after IWRP)	5,801	26%
Applicants or Clients of Independent Living Programs	248	1%
Applicants or Clients of Special Projects (non-VR)	138	1%
Applicants or Clients of Facilities (non-VR)	256	1%
Total	21,982*	100%

Source of Client Concern:	Total	% of Total
VR Agency only	8,853	66%
All Other Sources only	1,342	10%
Both VR Agency & And Another Source	2,208	16%
Unreported	1,063	8%
Total	13,466	100%

Major Disabling Conditions of Individuals Served:

	Total	% of Total
Blindness (both eyes)	844	6%
Other Visual Impairments	518	4%
Deafness	476	4%
Hard of Hearing	386	3%
Orthopedic Impairments	3,196	24%
Absence of Extremeties	226	2%
Mental Illness	2,014	15%
Substance Abuse (alcohol or other drugs)	518	4%
Mental Retardation	744	6%
Respiratory Disorders	156	1%
Heart & Other Circulatory Conditions	274	2%
Digestive Disorders	110	1%
Speech Impairments	110	1%
Genitourinary Conditions	62	0%
All Other Disabilities	3,141	22%
Disability Not Known	691	5%
Total	13,466	100%

Types of Services Provided:

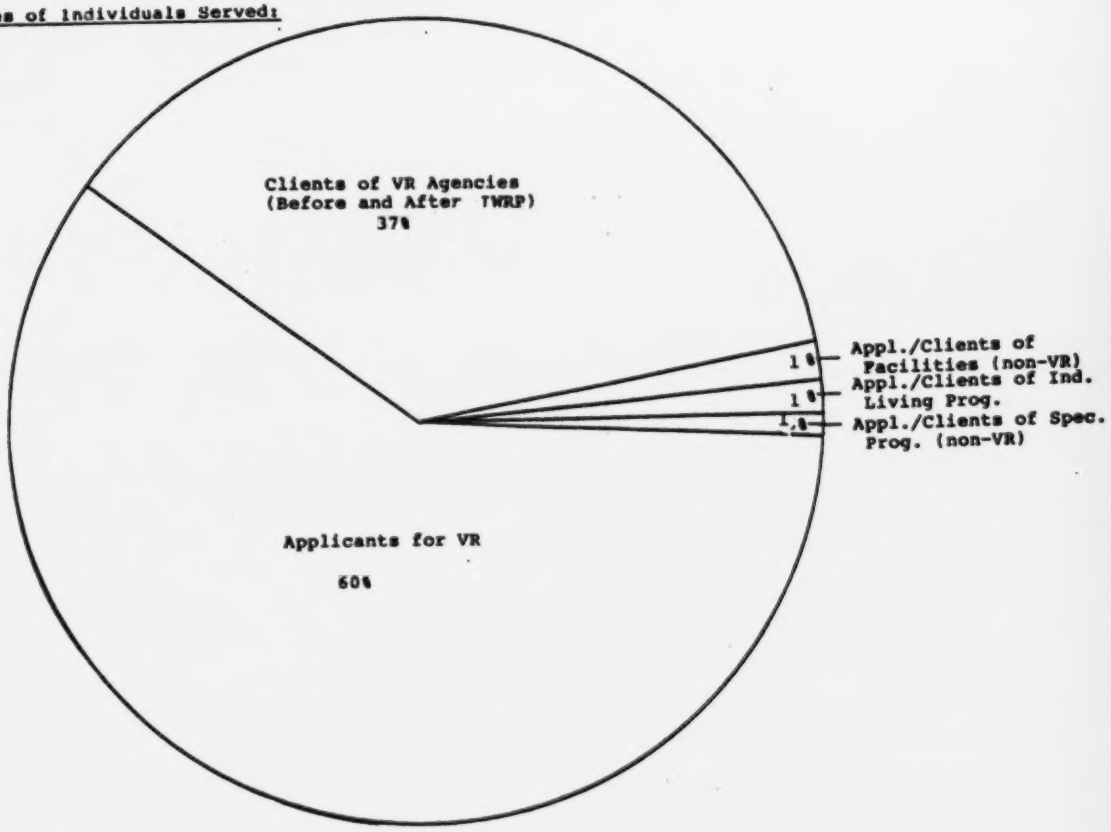
	Total	% of Total
Information & Referral	7,807	50%
Mediation/Administrative	5,853	37%
Legal	362	2%
Transportation	132	1%
Other	1,560	10%
Total	15,714*	100%

*Note that "types of individuals served", and "total types of services provided", exceed number of total clients. Some clients received more than one type of service.

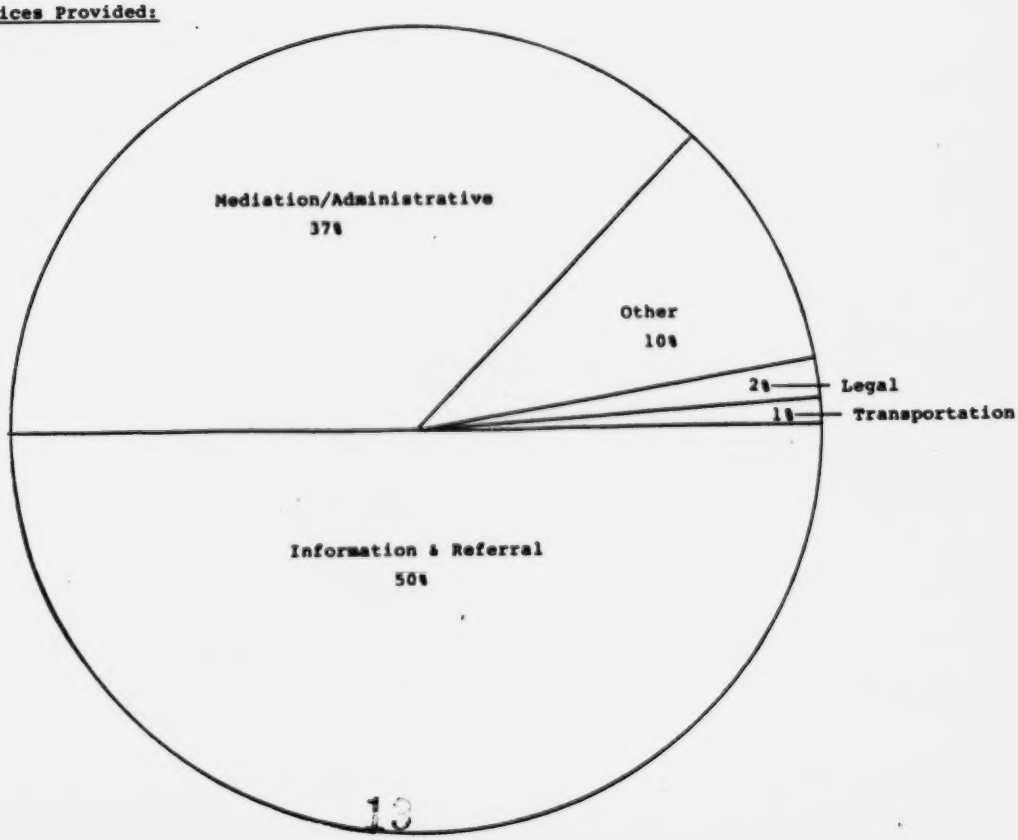
Client Assistance Program

1986 Annual Report

Types of Individuals Served:



Types of Services Provided:



Appendix III

Narrative Summary

The following summary contains anecdotal examples of CAP and P&A activities. States were chosen for inclusion in this report at random. This is not a comprehensive listing of all activities of these agencies but is offered here as an addition to individual cases in which agencies are involved.

ARIZONA: The Arizona Center for Law in the Public Interest has just completed its ninth year of providing advocacy and legal representation for people with developmental disabilities. The Center provides assistance to parents in several areas including obtaining appropriate educational programs for their children with developmental disabilities, assisting parents in preparing for IEP meetings, and negotiating to resolve disagreements between parents and school personnel. The Center also provides guardianship training clinics for parents. In the area of employment, the Center provides information and referral to individuals with disabilities who are subjected to discrimination in hiring, promotion or dismissal.

The Center's involvement in nine years of litigation concluded in 1986 with a precedent-setting decision on behalf of a client who was refused employment by the United States Postal Service because of epilepsy. The Center also successfully represented parents whose child was removed from their care at birth because the mother had a developmental disability.

The Center supported a class action case on behalf of Arizonans labelled chronically mentally ill. Although the Judge's favorable order required the state and county to provide appropriate community mental health services and awarded the Center attorney's fees and costs, state and county defendants have appealed the decision.

CALIFORNIA: Protection and Advocacy, Inc. (PAI) undertook a variety of activities to expand outreach and special services to target minority populations. These activities included direct legal representation for 100 clients and short term assistance to 652 clients of Asian (Korean and Vietnamese) and Hispanic populations. In addition, self-advocacy materials were distributed in Spanish, Chinese, Vietnamese, Korean, and Cambodian and for the first time in Braille.

During FY 1986, PAI produced a manual, "Disability Benefits and Work," which dealt with the rights, benefits and responsibilities of Californians with developmental disabilities who work, or attempt to work under the SSDI and SSI programs. PAI also produced two training tapes, "How To Do Your Own Fair Hearing" and "General Advocacy Skills," which can be borrowed or purchased.

COLORADO: The IHP project, which previously focused on IHPs for persons in institutions, has changed its focus to monitoring the development of the plans and the planning process in community programs. A manual has been drafted for parents, advocates, and service providers to use in assessing the quality of IHPs.

Attempting to deal with a cutback in funding for children in out-of-home placements sponsored by the Department of Social Services, the Legal Center worked with the state Association for Retarded Citizens (ARC) to draft

legislation to address out-of-home placements and permanency planning for children with developmental disabilities.

FLORIDA: One of the major systemic issues that resulted in litigation involved the policy of a developmental services agency which denies dental treatment to clients who live in their own homes. Although an administrative hearing resulted in the client's favor, the agency reversed the decision of the Administrative Hearing Officer. When the agency's order was appealed, the appellate court ruled that the agency's policy discriminated between clients residing at home and clients residing in the agency's facility. This was determined to be contrary to state law.

The Governor's Commission on Advocacy for Persons with Disabilities (GCAPD) continues to provide technical assistance to the Human Rights Advocacy Committee which is responsible for monitoring the implementation of a regulation concerning the use of psychotropic drugs in all state residential facilities and institutions. This regulation resulted from a 1981 case brought before the federal court by GCAPD in response to the death of a person receiving developmental services in a state institution for people with mental retardation.

HAWAII: In addition to the training and technical assistance on legal services for the elderly, which was provided under a grant from the Administration on Aging, Hawaii's P&A staff received in-service instruction on the various types of training methods available and participated in a workshop on "The Art of Negotiation." On the national level, the Executive Director of the Hawaii P&A was invited to testify before the Subcommittee on Select Education, U.S. House of Representatives, regarding the reauthorization of the Rehabilitation Act of 1973.

IDAHO: Recognizing the need to serve people with disabilities in rural areas, Idaho'S Coalition of Advocates P&A (CO-AD) developed a service delivery model which operates out of decentralized offices. When a Personal Care Services Medicaid Waiver option was implemented in Idaho four years ago as a result of litigation instituted by CO-AD and over 400 people who would otherwise have been institutionalized were discharged or "diverted", CO-Ad and others successfully pushed state service agencies into providing the resultant program.

Much of CO-Ad's legal work during 1986 revolved around the Personal Care Program, defining eligibility and expanding the program so that the state's implementation complies with federal requirements. CO-Ad was the recipient of the Epilepsy Foundation of America's 1986 "Advocacy of the Year" award.

INDIANA: The Indiana Protection and Advocacy Service Commission's (IPASC) training department, assisted by legal and program staff, trained over 1,677 persons in 1986. Specific trainings included a two day training program for front line staff in health care facilities, a three day program designed to train volunteers at a grass-roots level to become advocates for persons with developmental disabilities, and three sessions addressing educational programming mandated by state law to insure the provision of free appropriate public education.

KANSAS: Since Kansas Advocacy & Protection Services for the Developmentally Disabled, Inc. (KAPS) is the agency designated to implement the PAMI Program, the Executive Director and the PAMI Program Coordinator attended the training program on mental health issues sponsored by NAPAS in Denver. Information about KAPS' new MI P&A program was presented to approximately 30 people at the Kansas chapter's meeting of the Tourette Syndrome Association and to approximately 100 people at a meeting of Families Together in Manhattan. KAPS also coordinated a meeting of representatives of groups involved/interested in issues relating to persons with mental illness to advise on ways to implement provisions of P.L. 99-319 pertaining to the establishment of an advisory body.

KAPS has also provided services to persons with mental illness through the state-funded Kansas Guardianship Program, where approximately 22 percent of the 560 wards/conservatees served in the program have been diagnosed as having mental illness. (These statistics are not reflected in the 1986 statistical report on Kansas' PAMI program.)

KENTUCKY: Of the 792 people served in FY 1986 by the Office for Public Advocacy, Division for P&A, 491 were either institutionalized, at risk of being institutionalized, or deinstitutionalized.

The staff was also involved in drafting legislation for special education funding and a bill, which was passed, that establishes a right to services for persons with severe developmental disabilities.

The Kentucky P&A was successful in two federal district court lawsuits, one involving the restoration of SSI benefits to a person with Down's syndrome and the other involving summer school and reimbursement for evaluations and residential placement for a child who has an emotional disturbance. Progress was also made in two other cases in federal district court. One case involves four individuals with mental retardation who were wards of the State and the other involves the right to a free, appropriate public education.

LOUISIANA: The Center's Nursing Home Advocacy Project, also funded by SPCDD, has just completed a two-year survey to determine the number of nursing home residents with developmental disabilities who are under fifty-five (55) years of age. The purpose was to identify the services they were receiving and to assess their need for advocacy services. The project produced a final report, "Those Who Sit and Wait: Young People in the Nursing Homes of Louisiana."

The Advocacy Center, which also houses the PAMI Program and the Client Assistance Program (CAP), began developing plans for serving people with mental illness and soliciting suggestions for advisory committee members. CAP staff met with staff from the Department of Vocational Rehabilitation (DVR) in hopes of changing VR procedures by advocating to increase the economic scale used to determine a person's eligibility for DVR services. The CAP has also been successful in holding DVR to the regulatory requirement to publish proposed procedural changes, allowing for public comment. Likewise, the CAP is urging DVR to seek the opinions of recipients and providers of vocational rehabilitation (VR) services as well as others involved in VR issues in matters concerning general policy development and implementation.

MAINE: The Advocates for the Developmentally Disabled, Inc. (ADD), a free standing, private, non-profit agency, is the designated agency to implement the PAMI Program. Although PAMI funds were used to hire additional staff, the deletion of two staff positions resulted in a net gain of three staff. In preparation for the possible passage of P.L. 99-319, the agency undertook an internal planning process in December 1985. Public meetings were held; two of which were for specific public comment on a proposed Mental Health Advocacy Plan. Participants included State agencies, parent/consumer groups, provider agencies, and state advisory groups. The resultant plan, the "Mental Health Protection and Advocacy Plan," was approved by the Governor. Minutes, summaries, and staff papers were also produced. ADD staff also advocated for twenty-five bills in the State Legislature which would have an impact on persons with mental health problems.

MINNESOTA: MMHLP staff served on the Governor's Mental Health Commission and played a major role in drafting three pieces of proposed legislation for the Commission.

MMHLP and the Legal Advocacy Project for Hearing Impaired Persons worked together to represent four deaf persons with mental illness who were residing in a state hospital. The Judge handed down a favorable decision on the central issues, includeing non-compliance with staffing ratios. MMHLP is also representing one of the plaintiffs in a proceeding concerning transfer from the Minnesota Security Hospital and represented several teenagers who were hospitalized in psychiatric facilities by their parents under questionable circumstances and who were otherwise denied their rights. In addition, MMHLP continues to represent hospital residents with treatment-related concerns.

MISSOURI: The Missouri P&A staff have drafted legislation to establish a protective services system for adults with disabilities. They are also finalizing a draft of legislation to allow Missouri P&A Services access to clients' records in accordance with the legislation for protection and advocacy for individuals labelled mentally ill. Another piece of legislation is being drafted to provide for the implementation of surrogate parent requirements pursuant to Public Law 94-142 to provide training, to make appointments, and to maintain the quality of services of surrogate parents.

Missouri P&A Services entered into a legal contract with a law firm in order to expand and improve legal assistance for the agency, staff, and clients. Missouri P&A Services also assisted People First of Kansas City in providing outreach for the development of other chapters and for members of that group to receive self-advocacy training.

MONTANA: In June, Montana Advocacy Program (MAP) sponsored a statewide citizen advocacy seminar which addressed the need for advocacy; involvement by boards of directors; building of relationships between advocates and proteges; hints of effective advocacy; and the future of citizen advocacy.

Fourteen (14) of the 157 cases handled by MAP in FY 1986 required specific

intervention by staff attorneys. In one case involving appropriate education for a deaf child and requiring on-going litigation, MAP was able to support each student's right to receive a "mainstreamed" education.

NEBRASKA: Nebraska Advocacy Services, Inc., (NAS) was awarded a VISTA grant to provide eight VISTA volunteers to citizen advocacy programs in Nebraska. In addition to acting as the coordinating agency and training the volunteers, NAS has initiated the publication of a specialized national newsletter, Citizen Advocacy Share, which includes articles contributed by people involved in citizen advocacy across the country and is distributed to sixty-five citizen advocacy programs throughout the United States and Canada. NAS also provided assistance to People First of Nebraska, including training the membership and assisting with preparations for its annual convention.

During FY 1986, NAS continued to develop a series of one page papers entitled Law in Brief, covering 21 different topics including special education rights, financial entitlements, guardianship and employment discrimination. NAS has also published a 230-page manual on legal rights, Developmental Disability Law — A Manual for Nebraska Advocates, which can be used as a reference tool by anyone who advocates for people with developmental disabilities.

NEW HAMPSHIRE: During 1986, New Hampshire Developmental Disabilities Advocacy Center (NHDDAC) doubled from the previous fiscal year the number of individuals it served through training services addressing a variety of training topics. Slightly over 10 percent of the people trained were recipients of developmental services, with the remainder being advocates and service providers. In an effort to expand resources, NHDDAC increased its network of private attorneys by stimulating and increasing their interest in and knowledge of developmental disabilities.

NEW MEXICO: The Protection and Advocacy System, Inc., a private, non-profit agency, is responsible for implementing the protection and advocacy programs for persons with developmental disabilities and for persons labelled mentally ill in New Mexico. Using PAMI funds, four and a half staff positions (one attorney, two coordinators, a half-time advocate/paralegal, one clerical person and a PAMI Executive Director) were added to the P&A System during FY 1986. In-service training began with the Executive Director and three staff attending the mental health track of NAPAS' 1986 Annual Conference. In addition, the Executive Director and the Chair of the PAMI Advisory Committee attended NAPAS' training in Denver which addressed the implementation of protection and advocacy services for people with mental illness.

P&A staff provided input into the development of a rights booklet for recipients of mental health services and established the mandated Mental Health Advisory Committee, which held its first meeting in August. PAMI staffing, budget, and basic priority recommendations were in place by the end of FY 1986. One of the major accomplishments of the P&A System during this time was that staff had some impact on getting the state Vocational Rehabilitation Agency to identify the needs of persons with mental illness as a priority.

NORTH CAROLINA: During FY 1986, Governor's Advocacy Council for Persons with Disabilities North Carolina P&A (GACPD) awarded nine (9) mini-contracts to programs to conduct local advocacy efforts. GACPD and other local agencies and committees participated in the second Barrier Awareness Day where state and local officials assumed various disabilities for the day and were paired with assistants who actually had disabilities. In addition, GACPD sponsored a regional conference on the North Carolina employment discrimination law and developed and distributed three public service announcements on employment of people with disabilities.

OREGON: The Oregon Developmental Disabilities Advocacy Center (ODDAC) in conjunction with People First, continued its Community Rights Training Project, a grant funding the development of a six-part videotape series designed to teach adults with disabilities who live and work in the community about their rights and responsibilities.

During FY 1986, ODDAC initiated a class action suit seeking community services opportunities on behalf of training center residents who have severe to profound mental retardation and who are injurious to themselves and others. ODDAC filed a Motion to Intervene in a lawsuit filed by the U.S. Department of Justice against the State of Oregon concerning the lack of appropriate treatment, training and education at this training center. In representing a number of students who, due to behavior problems, had been placed on home instruction by the school district, ODDAC successfully negotiated appropriate school placements as well as corresponding residential placements when necessary. ODDAC was also successful in limiting the guardianship of several persons, allowing them to make their own decisions in residential and vocational options.

PENNSYLVANIA: The Minority Outreach Effort, which was revitalized during FY 1986, targeted the black populations in Pittsburgh and Allegheny County. After a successful outreach model has been developed, it will be transplanted to other geographic areas and other minority groups as well as being applied statewide.

The two law projects under contract with the Developmental Disabilities Advocacy Network (DDAN), The Education Law Center, Inc. and the Developmental Disabilities Law Project, initiated eight significant lawsuits during FY 1986 addressing issues such as enforcing the rights of children with disabilities under Section 504 of the Rehabilitation Act of 1973, meeting the needs of Southeast Asian children in areas such as special education evaluations and programs, school counseling, and bilingual education, and representing the constitutional rights of a woman with mild mental retardation who was illegally and wrongfully institutionalized for almost 30 years without any due process safeguards. In addition to monitoring state institutional facilities for persons who have mental retardation, DDAN has been involved in a suit filed against a center by the Public Interest Law Project of Philadelphia.

RHODE ISLAND: Rhode Island Protection and Advocacy System, Inc. (RIPAS) is co-counsel with the State Office for Child Advocacy in a suit against the Departments of Education and Children & Their Families, concerning the appointment and monitoring of surrogate parents for special education students in the care of the State.

RIPAS has been successful in expanding its resources by securing a grant from the R.I. Foundation to do outreach to minorities, hiring a black and an hispanic outreach worker for one year and producing brochures in English and Spanish. Another grant for $15,000 was obtained from the Prince Foundation to provide additional attorney time.

SOUTH CAROLINA: SC P&A System for the Handicapped, Inc.'s legal staff was involved in the design and presentation of training on the implementation of a Consent Order which resulted from SC P&A litigation against the Department of Mental Health. The consent order outlined the evaluation and treatment procedures to be used by the Department when serving children from the family court or the Department of Youth Services.

SCP&A sponsored workshops, gave speeches and conducted educational presentations on a variety of topics across the State. Specifically, SCP&A conducted eleven CAP workshops, entered into a cooperative agreement with the South Carolina Association for Retarded Citizens to begin education workshops, and co-sponsored two conferences, one on individuals with dual diagnosis and one on Advocates for Children.

During FY 1986, SCP&A was involved in filing a 504 complaint on behalf of clients of the Department of Mental Retardation alleging discrimination on the basis of their other handicapping conditions. SCP&A was also involved with individuals with handicaps residing in correctional facilities.

TENNESSEE: In addition to the central office located in Nashville, E.A.C.H. (Tennessee P&A) has regional staff in three other locations and plans to open two additional regional offices in FY 1987.

Within E.A.C.H., individual case advocacy is provided by volunteers and staff using a team advocacy approach. Volunteers, who were chosen from a pool of volunteers and assigned to individual cases, logged over two thousand hours on cases and training during FY 1986. Attorneys, both volunteer and staff, are assigned to the advocacy teams as needed and provide legal assistance on a case-by-case basis. All advocates participate in intensive training workshops and follow specific policies and procedures.

VERMONT: Legal cases handled by Vermont Developmental Disabilities Law Project involved issues such as least restrictive environment for early childhood education students, the reinstatement of a driver's license for a man who had been seizure-free for a long period of time, establishing that a person under guardianship can apply for a FHLA loan, compensatory special education services for a client over the age of 22, and emergency guardianship for a client residing in a substandard and abusive community care home. In addition, VDDLP became involved in a class action involving the sequential analysis used in the determination of Social Security Disability Benefits.

VIRGINIA: The Department for Rights of the Disabled (DRD) participated in several initiatives designed to expand opportunities for youngsters with developmental disabilities who are transitioning from the educational system to the vocational rehabilitation system.

During FY 1986, P&A/DRD began converting its information and referral services from a word processor to a computer. The data base will eventually contain information on approximately 4,000 organizations, agencies and facilities which provide services to persons with disabilities. The I&R staff also developed and categorized an extensive resource library available to staff, consumers, and service providers.

P&A/DRD publishes a quarterly newsletter which is distributed to approximately 7,000 people and produced an eight-minute videotape entitled "Know Your Legal Rights," which was distributed to 54 sheltered workshops serving people with developmental disabilities. In addition, both the 1986 edition of the Legal Rights Handbook and the legal rights brochure were taped and distributed to persons with visual impairments.

WISCONSIN: Wisconsin Coalition for Advocacy, (WCA) has developed several resources of interest including a report, "Out of Sight, Out of Mind: A Report on the Human and Civil Rights of Residents of Wisconsin's Three State Centers for the Developmentally Disabled." The report documents serious patterns of deficiencies and rights violations in Wisconsin's state-run institutions for persons with disabilities and includes a discussion of the dynamics of the "institutional model" of care which shapes practices in large institutions as well as specific recommendations in response to cited problems. WCA participated in a variety of follow-through activities related to this report, including meetings with representatives of the State Department of Health and Social Services and key legislators.

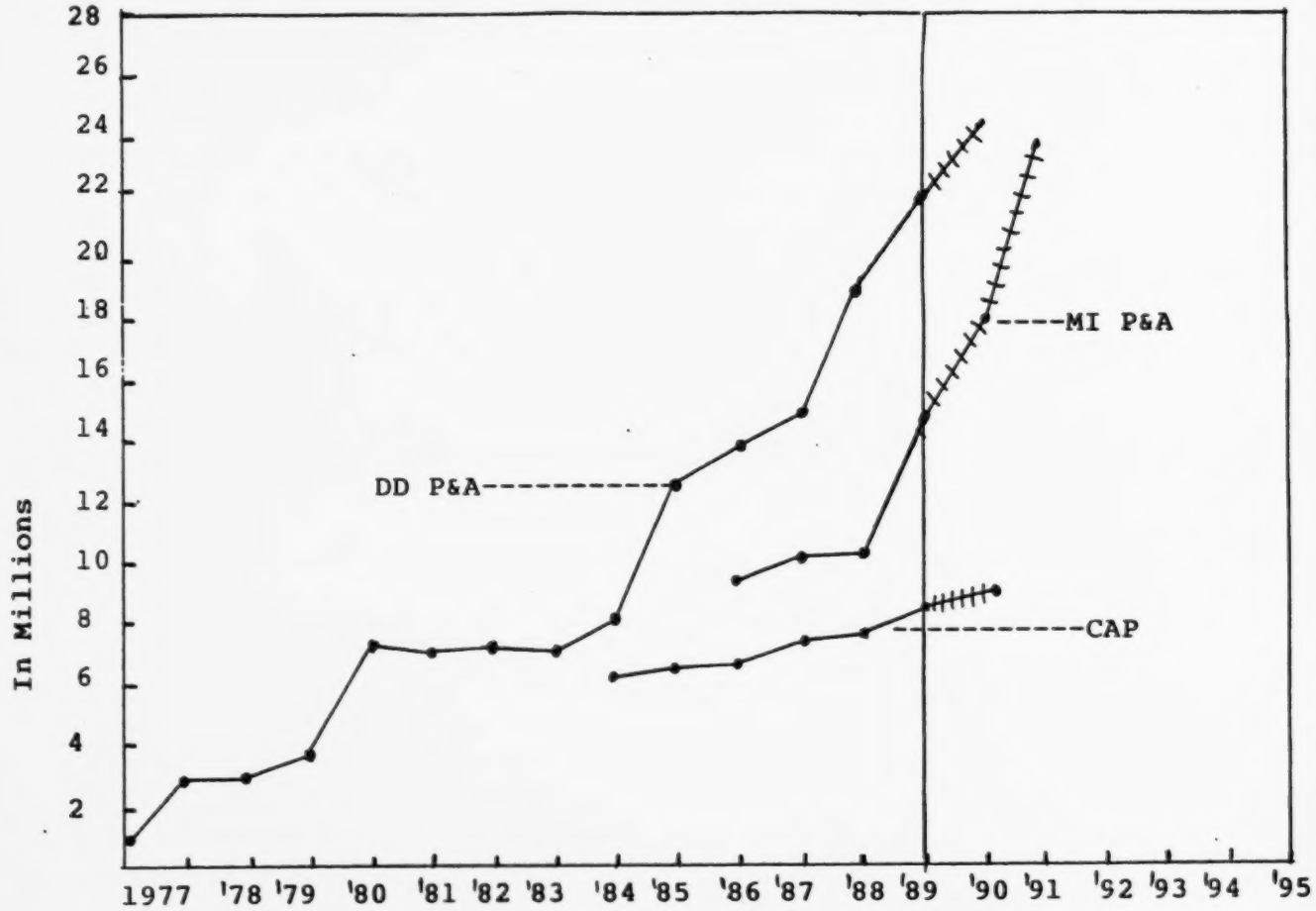
FY 1986 marked the second year of WCA's Institutional Advocacy Project funded by the Wisconsin Council on Developmental Disabilities. The project was designed to safeguard the rights of people with developmental disabilities and mental illness residing in institutions as well as providing advocacy to people living in selected institutions through subcontractual partnership arrangements with local advocacy organizations. WCA represented individuals in Brown County who were denied community services on the basis of their "behavior problems," worked with a coalition of disability organizations to increase funding and to expand Community Options and Community Integration Programs, and assisted in drafting legislation to protect against the abuse of vulnerable adults with disabilities.

WYOMING: DD/P&A handled several cases of interest during 1986. In a hearing before an Administrative Law Judge, DD/P&A succeeded in proving that a woman with borderline intellectual functioning, severe scoliosis, obesity, and epilepsy had a sufficient combination of impairments to be determined eligible for Supplemental Security Income benefits. DD/P&A also initiated an appeal on behalf of a woman with a dual diagnosis of mental retardation and mental illness to assist her in retaining her parental rights after signing a consent for adoption for her five year-old son. DD/P&A is also involved in a case concerning the appropriateness of the placement and habilitation program for a client with Prader-Willi Syndrome who was involuntarily committed to a state training school.

Program Funding Chart
1986-87 Annual Report

Appendix IV

- This chart reflects appropriated levels of funding for CAP, DD and MI P&A programs through fiscal year 1988.
- For 1989 and 1990, Congress has authorized the spending indicated for the CAP and DD P&A programs. The actual appropriation is pending.
- For 1989, 1990, and 1991, Congress is considering the indicated authorization level for the MI P&A program. Actual appropriation levels will be negotiated with the Administration.



NAPAS elected its Board of Directors in 1981. Part-time staff was hired in 1983. A full-time Executive Director and part-time Administrative Assistant were hired by NAPAS in 1986.

Positions of DD Project Director for Training and Technical Assistance and CAP Project Director, were created in the NAPAS office supported entirely by federal grants from the Administration on Developmental Disabilities and the Rehabilitation Services Administration respectively.

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National Association of Protection and Advocacy Systems

NAPAS is the membership organization of state Protection & Advocacy Systems (P&As) and Client Assistance Programs (CAPs). P&As serve people with developmental disabilities (DD P&A), and the Client Assistance Program supports people being served by state departments of vocational rehabilitation. In May of 1986, the Protection & Advocacy for Mentally Ill Individuals Act (PAMI) was passed by Congress. Federal funds for this new program were disbursed to state P&As in late 1986. Statistics on PAMI clients are compiled in NAPAS' 1987 Annual Report.

NAPAS is governed by a seventeen member Board of Directors (4 officers, 11 regional representatives, and two at-large members). Each program paying dues receives one vote per federal program.

NAPAS activities include monitoring Congressional action affecting persons with disabilities and vocational rehabilitation agencies, monitoring the administrative agencies responsible for P&A and CAP programs which include the National Institute of Mental Health, Rehabilitation Services Administration, and Administration on Developmental Disabilities. In addition, NAPAS provides a variety of training and technical assistance activities for its members which includes an annual meeting in Washington, DC. Also, NAPAS' liaisons with other federal agencies and national organizations allow coalition building and consensus on Congressional lobbying efforts.

NAPAS wishes to thank all those state P&A offices who provided their statistics and annual reports which made this report possible. Providing invaluable assistance on the compilation of this report were NAPAS staff members Shirline Davis, Marvin Harden, David Harvey and Sallie Rhodes.

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NAPAS

National Association of Protection and Advocacy Systems

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ANNUAL STATISTICAL REPORT

I. Protection & Advocacy for Persons with Developmental Disabilities

II. Client Assistance Program

III. Protection & Advocacy for Persons with Mental Illness

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May, 1988

Table of Contents

	Page
Introduction	1
Protection & Advocacy for Persons with Developmental Disabilities (DD P&A) Report	5
Client Assistance Program Report (CAP)	9
Protection & Advocacy for Persons with Mental Illness Report (PAMI)	13
NAPAS Program Funding Chart	17
DD P&A Narrative Summary	18
CAP Narrative Summary	21
PAMI Narrative Summary	24
State P&A Agency Addresses	27
CAP Agency Addresses	30
NAPAS Organizational Structure	31
NAPAS Board of Directors and Staff Members	32

National Association of Protection & Advocacy Systems
(NAPAS)

1987 Annual Report

Introduction

This NAPAS Annual Report summarizes program data for the State Protection & Advocacy Systems for Persons with Developmental Disabilities (DD P&A) and Mental Illness (PAMI), as well as the Client Assistance Program (CAP). The statistical portions of this report are derived from 55 states and territories reporting as required by the federal administering agency for each program.

In some cases, data are missing from state programs that failed to compile a report, or NAPAS was unable to obtain data prior to the deadline for this publication. In other cases, state programs provided data but certain categories of information were missing. This has been accounted for in statistical totals as indicated by "unreported".

A brief outline of the purpose, goals, funding levels and administering agency follow for the DD P&A, CAP and PAMI programs. The next section of this report contains statistical information organized according to federal reporting requirements established by the federal administering agency.

Subsequent sections include a program summary narrative with examples from several states. A program funding chart and list of state agency addresses and phone numbers follow.

Protection & Advocacy for Persons with Developmental Disabilities

This program was originally established by the Developmental Disabilities Act of 1977, which mandated that states provide advocacy services, including the ability to pursue legal, administrative and other appropriate remedies, to protect the rights of individuals with disabilities. The Governor in each state must designate a program to serve as the P&A System. The Governor must assure that the system is independent of any service provider, and is able to pursue legal remedies and has certain access to clients and their

records. The 1987 fiscal appropriation by Congress for DD P&A activities was $15.5 million.

Developmental disabilities are defined by the federal government as chronic and attributable to mental and/or physical impairments which are evident prior to age twenty-two. These disabilities tend to be life-long and result in substantial limitations in three or more of the following major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living, and/or economic self-sufficiency.

The administering agency for the P&A program for Persons with Developmental Disabilities is the Department of Health and Human Services, Administration on Developmental Disabilities.

Client Assistance Program

Section 112(a) of the Rehabilitation Act of 1973, as amended by the Rehabilitation Act Amendments of 1984 (29 U.S.C. 732), mandated the establishment of Client Assistance Programs (CAPs), reflecting the belief of Congress that persons with disabilities require assistance in obtaining information and access to services provided under the Act. The purpose of CAPS is to advise vocational rehabilitation clients and client applicants about all available services under the Act; to assist them in their relationships with projects, programs, and facilities providing rehabilitation services in the Department of Vocational Rehabilitation (DVR) under the Act; and to assist in this process through the use of legal, administrative and other appropriate remedies to ensure the protection of rights of DVR clients. The CAP program for 1987 was authorized by Congress at $7.1 million.

In many cases, CAPs are designated as part of the P&A system but others are independent agencies or part of departments of vocational rehabilitation. The Governor of each state has the authority to designate the CAP and is not allowed to redesignate CAP without demonstrating good cause. Failure to have a CAP program, would result in the loss of the state grant Vocational Rehabilitation program. The breakdown of CAP designation is as follows: 28 CAP agencies are externally designated to P&As; 11 CAPs are externally designated to other agencies; 1 CAP is externally designated to a for-profit agency (Alaska); 18 CAPs are internally designated to departments of vocational rehabilitation, and of these, 9 are housed inter-departmentally, 5 are subcontracted to other agencies by the department, and 4 subcontract to the state P&A system.

The administering agency for the Client Assistance Program is the Department of Education, Rehabilitation Services Administration.

Protection & Advocacy for Persons with Mental Illness

Modeled after the DD P&A, the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (P.L. 99-319) was passed in May of that year. Similar to the DD P&A, the Act established a system that protects the rights of persons with mental illness under federal and state statutes and creates a system to investigate abuse and neglect of persons in facilities. The system must be assigned to the DD P&A System. The individuals covered under the Act must reside in facilities which provide 24 hour care and treatment, or have been discharged from such a facility within the past 90 days. Monies became available at the end of 1986. 1987 represents the first full year of operation. The appropriation for FY 1987 was $10.5 million.

The administering agency for the P&A for Persons with Mental Illness is the Department of Health and Human Services, National Institute of Mental Health.

P&A and CAP Mission

P&A staff consist of attorneys, social workers and other advocates who are capable of providing a full range of advocacy services including the ability to pursue legal, administrative and other appropriate remedies to protect the rights of clients. The P&A programs must be independent of any service provider to assure conflict-free advocacy services. The Governor of each state designates the agency to fulfill the P&A mandate and cannot redesignate the program without good cause.

P&A activities include: (1) investigating, negotiating or mediating solutions to problems expressed by persons with developmental disabilities, persons with mental illness or clients of DVRs, their families or agency representatives; (2) providing technical assistance to attorneys, governmental agencies and service providers; (3) providing legal counsel and litigation services to persons in this population and groups who are unable to attain adequate or appropriate legal services in their communities; and (4) training advocates, consumers, volunteers, professionals, and other parties.

The P&A system works with institutions, including residential care providers, public and private hospitals for persons with mental illness or mental retardation, public schools and state correctional facilities in addition to a host of other service providers and governmental offices. The P&A system also provides advice and technical assistance to attorneys on such issues as disability and mental health law as well as providing assistance to various boards, commissions and government officials.

The CAP program works with State Departments of Vocational Rehabilitation and other agencies which receive funds under the Rehabilitation Act.

P&A for Persons with Developmental Disabilities

1987 Annual Report

CLIENTS SERVED

Number of Individual Clients Served	70,501
Number of Individuals Served Under Class Actions Where Number is Known	151,264

DEMOGRAPHIC DATA ON CLIENTS SERVED

I. Sex

	Total Clients	% of Total
Male	31,147	44%
Female	21,262	30%
Unreported	18,092	26%
Total	70,501	100%

II. Age of Clients Served:

Age	Total Clients	% of Total
0-4	5,345	8%
5-20	21,389	30%
21-64	21,259	30%
65+	2,545	4%
Unreported	19,963	28%
Total	70,501	100%

III. Geographic Location of Clients Served:

	Total Clients	% of Total
Urban (population of 50,000 or more)	19,636	28%
Rural (all other areas that have less than 50,000)	19,493	28%
Out of State (client's legal residence other than where P&A is located)	1,154	2%
Unreported	30,218	42%
Total	70,501	100%

IV. Client Living Arrangement:	Total	% of Total
Community Residential Home	5,068	7%
Foster Care	2,074	3%
Independent	6,144	9%
Nursing Home	2,008	3%
Parental or Other Family Home	22,759	32%
Public Institution	12,097	17%
Prison	469	1%
State School	2,197	3%
Private Educational Institution	732	1%
Other	2,531	4%
Unreported	14,422	20%
Total	70,501	100%

DISABILITY

V. Client Impairment:	Total	% of Total
Autism	1,386	2%
Cerebral Palsy	3,231	5%
Epilepsy	2,982	4%
Mental Illness	6,008	9%
Mental Retardation	25,192	36%
Multiple Sclerosis	506	0
Physical/Orthopedic	6,312	9%
Spina Bifida	380	0
Other	18,009	26%
Unreported	6,495	9%
Total	70,501	100%

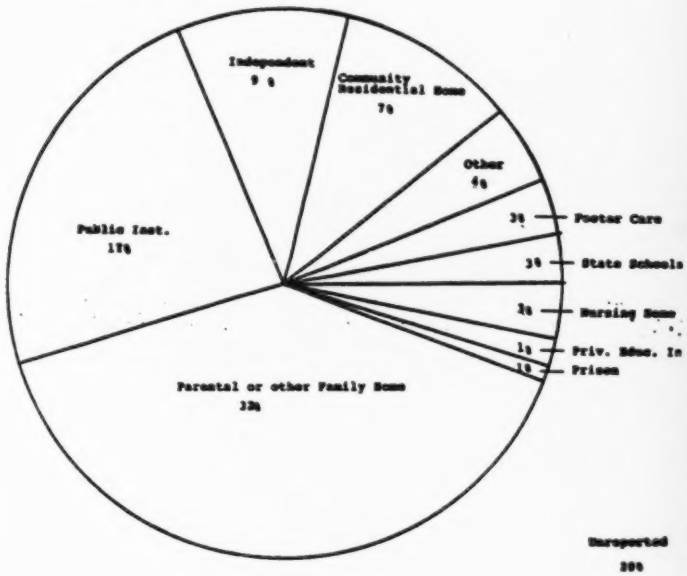
VI. Client Substantial Functional Limitation:	Total	% of Total
Self-Care	18,622	13%
Language	14,561	10%
Learning	30,748	21%
Mobility	10,916	8%
Self-Direction	22,113	15%
Independent Living	25,216	18%
Economic Self-Sufficiency	22,012	15%
Total	144,188*	100%

*Note that "client substantial functional limitation" exceeds total number of clients served. The federal definition of developmentally disabled requires three functional limitations.

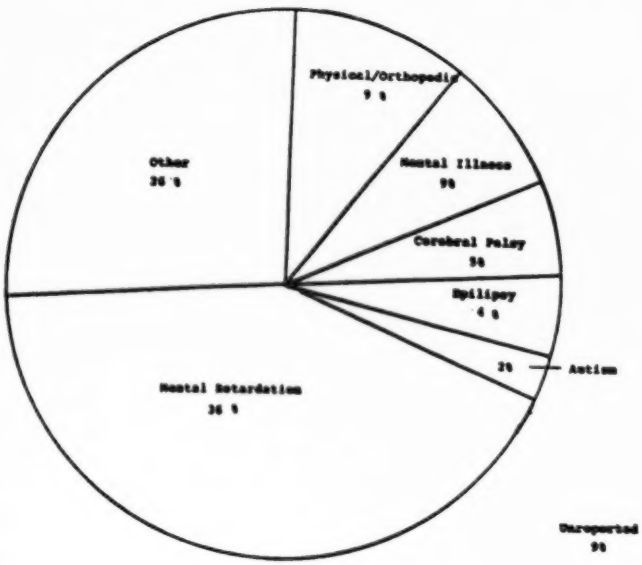
CLIENT PROBLEM AREAS

	Total	% of Total
Abuse/Neglect Exploitation	3,391	5%
Admission/ Commitment to Institution	1,347	2%
Architectural Barriers	1,931	3%
Conditions in Facilities	8,161	12%
Consent	267	0
Contracts/Ownership of Property	230	0
Criminal Justice Issues	920	1%
Day Care	413	0
Education	18,216	26%
Employment	2,149	3%
Financial Entitlements	4,445	6%
Guardianship/Conservatorship	2,743	4%
Habilitation Services	5,438	8%
Housing	2,803	4%
Insurance	435	1%
Medical Services/and or Mental Health Services	2,823	4%
Records (access to, confidentiality of)	632	1%
Rehabilitation Services	1,702	2%
Rights of Privacy	464	1%
Sterilization	213	0
Transportation (non-education related)	996	2%
Voting	33	0
Wills & Estate Planning	355	0
Zoning	140	0
Other (for example: foster care, respite care, legal harrassment)	10,254	15%
Total	70,501	100%

Clients Living Arrangement:



Client Impairment:



Client Substantial Functional Limitation:

Client Assistance Program

1987 Annual Report

TOTAL CLIENTS SERVED

Total Clients	Information & Referral
13,522	29,396

PROGRAM DATA

Types of Individuals Served:

	Total	% of Total
Applicants of VR	4,816	36%
Clients of VR Agencies	6,998	52%
Applicants or Clients of Independent Living Programs.....	390	3%
Applicants or Clients of Special Projects (non-VR).....	77	0
Applicants or Clients of Facilities (non-VR)	568	4%
Unreported	703	5%
Total	13,552	100%

Source of Client Concern:

	Total	% of Total
VR Agency only	9,207	68%
Other Rehab Sources only	1,398	10%
Both VR Agency & Other Sources (Rehab Act)	2,466	18%
Unreported	481	4%
Total	13,552	100%

Problem Areas:*	Total	% of Total
Client-Staff Conflict	1,490	11%
Service Related	3,949	29%
Related to Client's Eligibility/Application	1,365	10%
Other Problems	1,783	13%
Non-Rehabilitation Act Related	1,963	14%
Unreported	3,002	23%
Total	10,550	100%

*Note: problem areas are newly requested data on the 1987 federal CAP reporting form.

Major Disability of Individuals Served:

	Total	% of Total
Blindness (both eyes)	804	6%
Other Visual Impairments	576	4%
Deafness	550	4%
Hard of Hearing	364	3%
Orthopedic Impairments	3,437	25%
Absence of Extremeties	200	1%
Mental Illness	1,959	14%
Substance Abuse (alcohol or other drugs)	600	4%
Mental Retardation	587	4%
Learning Disabilities	462	3%
Other Neurological Disorders	729	6%
Respiratory Disorders	101	1%
Heart & Other Circulatory Conditions	237	2%
Digestive Disorders	88	1%
Speech Impairments	98	1%
Genitourinary Conditions	53	0
All Other Disabilities	1,874	14%
Disability Not Known	597	5%
Traumatic Brain Injury	236	2%
Total	13,552	100%

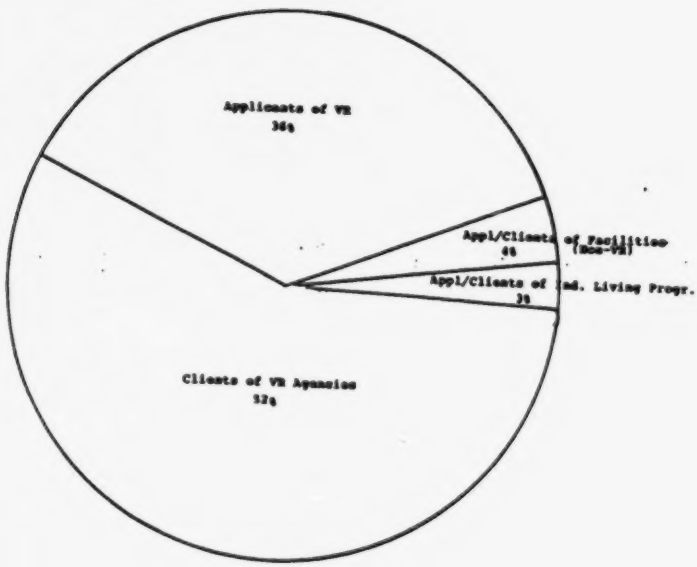
Types of Services Provided:	Total	% of Total
Information & Referral	7,611	52%
Legal	382	38%
Transportation	145	2%
Mediation	5,528	1%
Administrative	973	7%
Total	14,639*	100%

*Note that "types of services provided" exceed number of total clients. Some clients received more than one type of service.

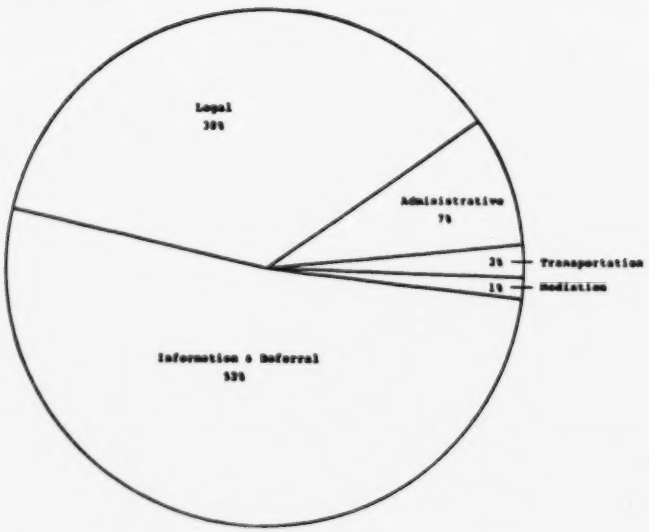
Client Assistance Program

1987 Annual Report

Types of Individuals Served:



Types of Services Provided:



P&A for Persons with Mental Illness (PAMI)

1987 Annual Report

Client Demographics

Individuals and Client Groups Served:

	Total
Number of Individual Clients Served (not including those served in group settings)	9,758*
Number of Individuals Served Under Class Actions (where number is known)	9,048

Client Classification:

MI Only	7,381
MI & DD	611
Total	12,315*

*Note that total MI and MI & DD clients exceed "number of individual clients served" and "number of individuals served under class actions". Some states reported number of individuals served under class actions in client classification totals, whereas some states only classified individual clients served.

Age of Individual Clients:

	Total	% of Total
0-20	1,379	14%
21-64	7,673	79%
65 & over	381	4%
Unreported	325	3%
Total	9,758	100%

Sex of Individual Clients:

Male	5,701	58%
Female	3,940	41%
Unreported	117	1%
Total	9,758	100%

Individual Clients' Geographic location:	Total	% of Total
Major Metropolitan Area (500,000+)	1,951	20%
Urban (50,000 to 500,000)	3,832	39%
Rural (less than 50,000)	3,170	32%
Out of State	48	0
Unreported	757	9%
Total	9,758	100%

Ethnic Background of Individual Clients:	Total	% of Total
White/Caucasian	3,276	34%
Black/Negro	1,313	13%
Hispanic	194	2%
Asian Pacific Islander	108	1%
Native American/Indian	46	0
Other	61	1%
Unreported	4,760	49%
Total	9,758	100%

Client Living Arrangements: (at time of intake)	Total	% of Total
Community Resident	598	6%
Homeless (includes shelters)	181	2%
Independent	987	10%
Parental, Foster Care or other Family Home	850	9%
Nursing Home (includes ICFs, SNFs, etc)	130	1%
Prisons/Jails	174	2%
Private Hospital or Treatment Center (includes psychiatric and general hospitals, private educational institution)	533	5%
Public Hospital or Treatment Center (excluding public educational institution)	5,410	56%
State Schools (i.e., public educational institution)	20	0
Other	564	6%
Unreported	311	3%
Total	9,758	100%

Case Problem Areas of Individuals Served

(Since one individual may have more than one problem, overall total may exceed total number of individuals served.)

	Subtotal	% of Subtotal
A. Alleged/Reported Abuse		
Exploitation (financial, physical, emotional)	333	10%
Inappropriate or Excessive Medical Treatment (medication, sterilization, etc.)	908	28%
Inappropriate or Excessive Physical Restraint, Isolation or Seclusion	546	18%
Physical Assault	393	12%
Sexual Assault	141	4%
Verbal Abuse	142	4%
Other Abuse (e.g. abduction, coercion, inciting clients)	737	24%
Subtotal	3,200	100%
B. Alleged/Reported Neglect		
Failure to Provide for Appropriate:		
Admission to Institution	1,070	16%
Community residential Placement	543	8%
Community Services (e.g. day care, independent living skills, job training/placement, social activities)	543	8%
Medical/Mental Health Treatment	1,254	20%
Release From Institution	791	12%
Discharge Planning	934	14%
Personal Care (e.g. personal hygiene, clothing, food, shelter, environment, etc.)	949	15%
Number of deaths resulting from abuse or neglect reported to agencies	251	4%
Other	187	3%
Subtotal	6,522	100%

C. Protection Of Rights

Types of Services Provided:	Subtotal	% of Subtotal
Contracts/Ownership of Property (includes wills & estate planning)	119	3%
Education	421	9%
Employment	239	5%
Finances & Reimbursements (e.g., SSI, SSDI, insurance)	918	20%
Guardianship/Conservatorship	346	8%
Housing	352	8%
Legal Representation	228	5%
Privacy (including right to congregate, telephone, mail, visitors, etc.)	390	8%
Records (includes access to, consent, corrections, confidentiality, etc.)	189	4%
Other	1,404	30%
Subtotal	4,606	100%

**Grand Total of All Case Problems This Year: 14,328

Intervention Strategies Used To Resolve Client Problems:
(Since more than one service/intervention may be used to resolve a particular problem and since an individual client may be experiencing more than one problem, the total number of interventions used may exceed the number of clients served.)

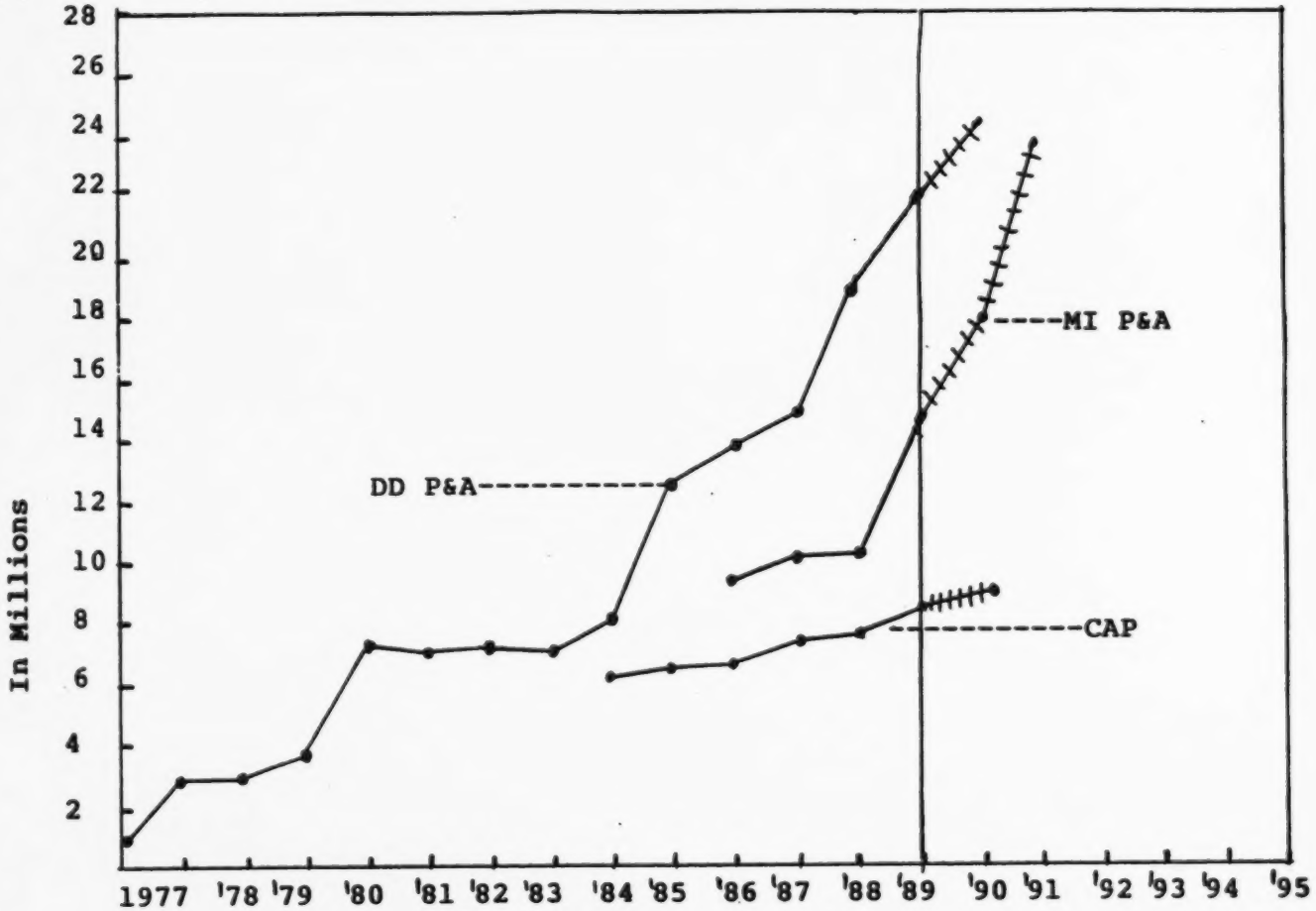
Supervised Referrals.....	1,920	6%
Counselling/Professional Assistance.....	4,820	14%
Complaint Investigation (includes follow up).....	3,136	9%
Administrative Remedies.....	1,210	4%
Negotiation/Mediation.....	20,002	58%
Legal Consultation (i.e., used only in conjunction with another service).....	1,245	4%
Litigation.....	148	0%
Unreported.....	1,941	5%
Total	34,442	100%

Non-Case Directed Services:

Total Information/Referral Services	15,114	
Number of Education & Training Activities	1,530	
Total Number of Persons Educated/Trained	30,108	
PAMI Involvement of Consumer Organizations	30-yes	1-no

Program Funding Chart
1986-87 Annual Report

- This chart reflects appropriated levels of funding for CAP, DD and MI P&A programs through fiscal year 1988.
- For 1989 and 1990, Congress has authorized the spending indicated for the CAP and DD P&A programs. The actual appropriation is pending.
- For 1989, 1990, and 1991, Congress is considering the indicated authorization level for the MI P&A program. Actual appropriation levels will be negotiated with the Administration.



NAPAS elected its Board of Directors in 1981. Part-time staff was hired in 1983. A full-time Executive Director and part-time Administrative Assistant were hired by NAPAS in 1986.

Positions of DD Project Director for Training and Technical Assistance and CAP Project Director, were created in the NAPAS office supported entirely by federal grants from the Administration on Developmental Disabilities and the Rehabilitation Services Administration respectively.

Narrative Summary

1987 Annual Report

The following narrative summary contains anecdotal examples of CAP and P&A activities for fiscal year 1987. States were chosen for inclusion in this report at random. This is not a comprehensive listing of all activities of these state agencies but is offered here to indicate types of activities other than individual cases in which P&As are involved.

Protection & Advocacy for Persons with Developmental Disabilities

Alabama Disabilities Advocacy Program (ADAP) handled a major non-legal case involving families of several hearing impaired students in north Alabama after the local school system summarily changed these children's classroom placements without convening an IEP committee meeting as required by P.L. 94-142. As a result of this action, the students had neither deaf education resources nor support services. After intensive negotiations and consultation with a recognized expert in the area of education for persons with hearing impairments, a variety of educational services was obtained.

ADAP is involved in ongoing litigation in Hough v. Department of Youth Services, et al., in which a settlement was reached on most major issues. The major points of the settlement include the construction of a new facility within three years, a schedule for prompt transfer of juveniles from the detention home, and the provision of far more extensive educational services than were previously being provided. ADAP has been involved in other litigation that is still pending as well as publishing several articles in such journals as Mental and Physical Disability Law Reporter.

Mississippi Protection & Advocacy System (MPA) has conducted numerous public presentations and distributed brochures and newsletters. MPA has been involved with several legal cases including whether or not a state owned Medicare/Medicaid recipient hospital can refuse to provide life sustaining dialysis treatment to a DD/MI person based on his use of abusive language, verbal threats and noncompliance.

Other cases have included a class of residents with mental retardation at a state operated mental retardation facility, who did not have easy, private access to their Protection & Advocacy attorney and whose records are not readily accessible to those attorneys. P&A staff cannot visit the MR facilities nor any of its residents without first giving 24 hours notice and giving the names of residents with whom staff members wish to talk or whose records are being requested.

Montana Advocacy Program resolved the case of D.T. in a manner satisfactory to the client. This young man had been at the Montana Developmental Center for over a year on a "voluntary" basis while awaiting a community placement. MAP had been back to district court monthly with him, there to hear SRS tell the judge that they were attempting to comply with the court order to place D.T. in the community "as soon as practicable", but that there were no appropriate openings in the State. At the end of last year, MAP obtained an Order to Show Cause from the judge directing the State to explain why it was not in contempt of court. Shortly afterwards, D.T. was placed in an appropriate group home in Billings.

New York Commission on Quality of Care for the Mentally Disabled (Protection & Advocacy for the Developmentally Disabled- PADD) together with New York Lawyers for the Public Interest, submitted an amicus curia brief in a case brought before the U.S. Supreme Court. The brief was submitted on behalf of the entire NYS PADD Program, the American Public Health Association, the American Civil Liberties Union, the American Nurses' Association as well as the National Association of Protection & Advocacy Systems. In its decision, the Supreme Court ruled 7-2 in favor of the defendant finding the persons with tuberculosis could be properly considered as handicapped for purposes of rights protection under Secion 504 of the Rehabilitation Act of 1973.

Ohio Legal Rights Service has provided funding for ODDASE, a statewide coalition of consumer/advocacy organizations representing the population of persons with developmental disabilities who do not have mental retardation in Ohio. ODDASE is in the process of developing a self-advocacy "package" of information and training materials which is being developed based on a broad view of self-advocacy activities across the country.

Pennsylvania Protection & Advocacy, Inc. (PPA) developed a multi-outreach fact sheet specifically designed for outreach to minority community groups, churches, and other minority focused agencies. PPA attended many minority community based meetings in which information about protection and advocacy services was disseminated.

The first role is to reach the minority communities; the second role is to assist individuals from the minority population to access needed services and remain in the system to receive the services—A service system problem is that minorities will not access nor remain in the system to receive the services.

South Carolina Protection & Advocacy System for the Handicapped, Inc. undertook the formation of an Ad Hoc Advisory Committee of consumers and parents. Members of the group include representatives from consumer organizations representing persons with disabilities from the following groups: blind, head injury, polio, mental retardation, autistic, learning disabilities, deafness, mental illness, epilepsy, and spinal cord injuries.

The committee has been meeting each month for the last year to discuss their concerns and to develop a list of problem areas to be discussed with the appropriate rehabilitative agency.

South Dakota Advocacy Project, Inc. successfully argued that Individual Indian Money (IIM) Accounts could not be considered a resource until the time the money was actually in the control of the individual, not while it was in the account or being petitioned for.

IIM accounts are established for the benefit of Native Americans from various sources relative to their status as an enrolled member of an acknowledged tribe or entity. Usually the individual does not have unlimited access to their account. Rather it is held for the individual and distributed for his/her benefit upon request or other application to an official, usually the reservation superintendant or his designee. The Advocacy Project intervened when it was determined by the state review office that IIM accounts were to be considered a resource, regardless of the fact that the person often could not access his/her account in an unlimited way.

Texas' Advocacy, Inc. has closed the litigation involving City of Cleburne V. Cleburne Living Center and is now collecting attorneys' fees and damages for the Cleburne Living Center. Advocacy,Inc. has successfully used the OCR complaint process to force four separate school districts to discontinue "placement by disability" practices of children with disabilities into segregated special education campuses.

West Virginia Advocates for the Disabled (WVADD) has been active in the area of early intervention. The last year of a two year phasein program serving three and four year old preschool children with severe handicaps began September 1, 1987. WVADD worked extensively with early intervention

(birth-two) providers and parents in training regarding the provision of educational services to pre-school children with handicaps. Problems encountered included a six month referral process on least restrictive environment. Procedures for speedy referrals and more appropriate placements were priority issues.

Wisconsin Coalition for Advocacy (WCA) was active in training and providing technical assistance to attorneys who review the placement of persons with mental incompetence in nursing homes and institutions. Under Wisconsin law, the placements of these individuals must be reviewed annually by a court. Training and technical assistance include publication of the Guardian Ad Litem Handbook, individual seminars, and consultation on individual cases.

Years of advocacy with the state Department of Health and Social Services culminated in the issuance of HSS 94, a detailed rule implementing S. 51.61, Wis. Stats., the bill of rights under the state mental health act for people living in state institutions and community programs. While HSS 94 does not apply in nursing homes and group homes, efforts to exempt nursing homes from S. 51.61 itself were defeated and DHSS has agreed to work on a uniform bill of rights for all facilities.

Client Assistance Program

Colorado Client Assistance Program helped to sponsor an orientation session for new vocational rehabilitation counselors with the Continuing Education Office, University of Northern Colorado at Greeley. Counselors were in attendance from the states of Colorado, Utah and Montana. The Division also sponsored a similar meeting with the Colorado Legal Center for VR counselors in the Denver metropolitan area.

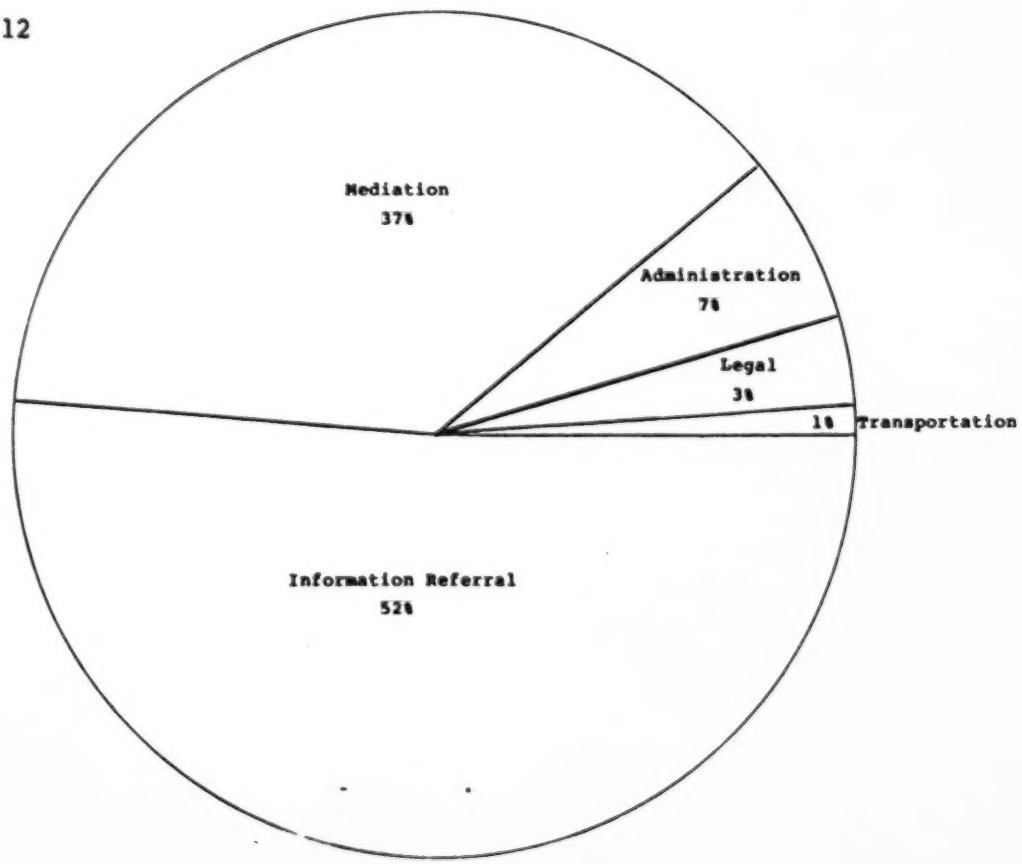
Louisana's Advocacy Center for the Elderly and Disabled has advocated for two years for an increase in the DRS economic need scale which is used to determine a client's eligibility for services contingent on financial need. In response to CAP's efforts, DRS submitted a substantially increased economic need policy to the Office of Human Development. The proposed increase was accepted and finalized in February, 1987. In addition to the increased scale, CAP was successful in prompting DRS to develop a policy which allows "automatic economic need eligibility" for all persons with disabilities on Supplemental Security Income (SSI).

C O R R E C T I O N S

Page 11

Types of Services Provided:	Total	% of Total
Information & Referral	7,611	52%
Mediation	5,528	37%
Administration	973	7%
Legal	382	3%
Transportation	145	1%
Total	14,639*	100%

Page 12



The agency participated in public hearings held by state rehabilitation agencies to allow for comment on the attachments to the state plan. Three hearings were held by the General VR agency and one by the VR agency serving persons who are blind. This CAP remains actively involved with these agencies as they rewrite their policy on client appeals to comply with changes in the 1986 Amendments to the Rehabilitation Act.

North Carolina CAP (NCCAP) reports that a recent change in general VR policy has reulted in a decrease in "single service" cases handled by VR field counselors, i.e., payment of a medical bill only as opposed to development of a comprehensive rehabilitation program which outlines the need for multiple services. This change has required some adjustment for rehabilitation staff, clients, and vendors. NCCAP has had the opportunity to review a number of cases which have arisen as a result of this change. In some instances, after talking with the client, NCCAP has identified other disability/employment related needs which were not initially identified by the rehabilitation staff. In such cases, the original denial of services has been reconsidered and a rehabilitation program has been developed. In other situations, NCCAP has assisted the VR staff and/or client to locate other resources which could more appropriately meet the client's need.

Oklahoma Client Assistance Program sponsored a workshop entitled "The Rehabilitation System: Inside/Outside/ Upside-Down". Participants included consumers, RVS staff, and representatives of numerous agencies involved in the rehabilitation process. This workshop included agency presentations, problem-solving techniques, models for successful rehabilitation programs, and role-play case simulation.

Utah Client Assistance Program was asked by the state Department of Rehabilitative Services (DRS) to assist with and participate in an in-service training program to prepare agency personnel to participate in the administrative appeals process. A full-day training session was organized and provided at eight different sites across the state. Most DRS personnel participated in this training. The Legal Center for the Handicapped provided assistance by participating in the making of a video tape depicting a mock Fair Hearing.

Utah CAP is continuing its discussions with DRS to refine the mechanics of the procedures established for the administrative appeals process. The training conducted in cooperation with the agency did much to heighten the awareness of clients' right to due process.

Idaho Client Assistance Program had a representative sit on the advisory panel of the new Bannock-Shoshone Reservation Vocational Rehabilitation program. There are well recognized barriers to the provision of any sort of social services on reservations by persons who are not Indians. Idaho CAP continued advocacy on behalf of two clients with mental illness who posed particularly difficult problems. Both individuals continue to make progress towards vocational goals. In part due to the CAP's efforts in highlighting the agency's need to be more aware of the unique aspects of this client population, the Idaho Division of Vocational Rehabilitation is conducting a special study of the needs of clients with mental illness and how to improve its service to them.

Indiana Advocacy Services (IAS) meets regularly with administrators of the vocational rehabilitation program to discuss issues of concern. IAS identified inappropriate applications of "time-in-status" guidelines with disadvantaged clients. For example CAP pointed out that clients in status 20 on facility waiting lists were often closed, if the duration of the wait would be expected to exceed the guideline for how long a client may remain in status 20. This practice resulted in clients needing to reapply to VR for an abbreviated diagnostic study when a vacancy occurred at the facility.

Maryland Client Assistance Program has an agreement with the Protection and Advocacy organization, otherwise known as the Maryland Disability Law Center, to ensure that individuals with disabilities have access to legal services, when appropriate, to assist them in the resolution of rehabilitation concerns. This fulfills one mandate of the Rehabilitation Act.

Wisconsin Client Assistance Program is distributing 3,200 complimentary copies of the manual, Rights and Reality: An Action Guide to the Rights of People with Disabilities in Wisconsin to clients, covered agencies and rehabilitation provider agencies. There are four versions of the manual including a detailed version with legal references, a general version with simplified language, a large print version and a taped version with a brailled index.

Protection & Advocacy For The Mentally Ill

Alabama Disabilities Advocacy Program (ADAP) assembled a "six person task force", including two consumers, two service providers and two mental health organizations to help locate and involve consumers on the ADAP Advisory Board. In addition, students from the Law School Clinical Program at the University of Alabama assisted with investigation and research on case work with the agency. Internships and fellowships were offered to graduate students in the School of Social Work and the Department of Psychology.

Alaska Advocacy Services (ASK) worked with state agencies to encourage the development of treatment programs in the least restrictive settings for individuals with dual diagnosis confined for committing sexual offenses against children.

ASK intervened in Weiss v. Alaska, which argued that the state of Alaska should use a lands trust established by the federal government in the 1950s to finance mental health services. In June 1987, the legislature passed a bill reconstituting the trust and making reparations.

Arkansas Advocacy Services, Inc. (Mental Health Advocacy Program- MHAP) has been involved with several situations which could provide a basis for class action in the next year. Investigation by MHAP staff disclosed that none of the local hospital psychiatric units have a patient advocate position, nor do they have a formal complaint procedure available to patients. Since the State Hospital does provide both of these safeguards, equal protection is being withheld from persons in the local hospitals.

This situation was brought to the attention of the State Mental Health Authority by the end of the project year. It is anticipated that resolution of this inequity within the early part of the next project year will benefit all persons who receive psychiatric treatment in these local hospitals.

Connecticut's Office of Protection & Advocacy (OPA) spearheaded a committee that worked to stop the construction of a jail on the grounds of a state psychiatric hospital. It reviewed and made recommendations on the Department of Mental Health's policy on the role of advocates in interdisciplinary treatment team meetings at state psychiatric facilities. OPA also negotiated to allow clients at facilities to attend these treatment team meetings.

Hawaii Protection & Advocacy Agency monitored both clients and buildings at Waimano Training School and Hospital (WTSH) and the investigation of alleged incidents of abuse/neglect brought about an almost two fold increase in Resident's Rights and Human Rights Committee concerns. A report, complete with recommendations, was also prepared on WTSH in preparation for distribution during the upcoming legislative session.

Idaho Coalition of Advocates for the Disabled (CO-AD) was involved in situations of inappropriate commitment of juveniles. Idaho's only state operated inpatient facility for juveniles with emotional disturbance is located in a state mental hospital. In addition, funding for foster care and other federally funded treatment alternatives are available only (due to the wording of Idaho's Title XX block grant) for those committed to state custody. As a result CO-AD has received requests to resist commitment actions under the State Mental Health and Child Protection Acts which seem primarily designed to access services, rather than protect clients or society from harm.

In at least two cases, services the client desperately wanted were available only if they were committed. In one case, the client's decision was to be committed. In the other, CO-AD assisted in developing a matrix of services (guardianship, counseling, SSI eligibility, school) to allow a 16-year-old to return to a community placement from a private hospital, rather than a year long placement in the state hospital, which had been recommended by a designated examiner.

Kentucky Protection & Advocacy (KPA) is currently involved in an investigation of the practices of hospitalization of children in foster care who are committed. A very high proportion of children in Kentucky are wards of the state. Based on an anonymous referral, KPA initiated an abuse/neglect investigation on behalf of 12 children who were allegedly hospitalized through "administrative order", over the objection of staff psychiatrists. In addition, children who have been placed in public and private hospitals are often left for long periods of time while the local field services worker is attempting to locate an appropriate, lesser restrictive placement.

The investigation has taken hundreds of hours, with interviews of over 20 individuals regarding the systemic practices of individuals responsible for providing the systemic practices of individuals responsible for providing services to children who are committed. KPA anticipates that this will significantly affect the quality of services for these children.

Maryland Disability Law Center (MDLC) assisted private facilities in the development and implementation of patient grievance procedures. MDLC was involved in Lisa L. v. Wilzack, a class action suit charging the state with failure to provide adequate community treatment for adolescents who were or had been confined to state psychiatric facilities.

Mississippi Protection & Advocacy Services, Inc. interceded in a dispute between a residential care facility and the Department of Mental Health by acting as guardian ad litem for 36 residents who were initially being forced to move by the Department. Because of P&A's involvement, no clients were forced to move who retained the ability to make their own decisions and who elected to remain in their current placement.

P&A's involvement further benefitted residents because many of the proposed placement facilities were found to be in recent violation of licensing regulations: one had become bankrupt, and others were inappropriate and more restrictive than required by the individual. P&A insisted that clients who opted to move be provided optimal information about the proposed placement to allow for a decision based on informed consent.

26:29

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The National Association of Protection & Advocacy Systems

NAPAS is the membership organization of state Protection & Advocacy Systems (P&As) and Client Assistance Programs (CAP). P&As serve people with developmental disabilities (DD P&A), and the Client Assistance Program helps people being served by state departments of vocational rehabilitation. In May of 1986, the Protection & Advocacy Act for Mentally Ill Persons (PAMI) was passed by Congress. Federal funds for this new program were disbursed to state P&As in late 1986 and statistics for the first full year of operation —1987—are reflected in this report.

NAPAS is governed by a seventeen member Board of Directors (4 officers, 11 regional representatives, and two at-large members). Each program paying dues receives one vote per federal program.

NAPAS activities include monitoring Congressional action affecting persons with disabilities and vocational rehabilitation agencies, monitoring the administrative agencies responsible for P&A and CAP programs which include the National Institute of Mental Health, Rehabilitation Services Administration, and Administration for Developmental Disabilities. In addition, NAPAS provides a variety of training and technical assistance activities for its members which includes an annual meeting in Washington, DC. Also, liaisons with other federal agencies and national organizations allow coalition building and consensus on Congressional lobbying efforts.

NAPAS wishes to thank all those state P&A offices and CAP programs who provided their annual statistics which made this report possible. Providing invaluable assistance on the compilation of this report were NAPAS staff members Shirline Davis, Marvin Harden, David Harvey, and Sallie Rhodes.

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26:5